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# Exploring Social Worker Knowledge, Conceptualization, and Use of Cultural Humility in Hospice

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Shelby Schiller

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The Office of the Provost

Walden University 2019

#### Abstract

Exploring Social Worker Knowledge, Conceptualization, and
Use of Cultural Humility in Hospice

by

Shelby L. Schiller

MSW, Loma Linda University, 2016

MS, Loma Linda University, 2016

BSW, California State University Los Angeles, 2014

Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Social Work

Walden University

November 2019

#### Abstract

This capstone project examined social workers' knowledge, values, and beliefs as related to the concept of cultural humility to determine how hospice care professionals treat patients' cultural preferences and traditions with respect and sensitivity at the end of life; as such practices have the ability to improve the hospice experience. Research questions addressed in the study (a) how social workers in Nevada define cultural humility in the context of hospice social work practice, (b) the values or principles hospice social workers in Nevada consider most important in providing culturally appropriate care to hospice patients, and (c) the ways hospice social workers in Nevada implemented a cultural humility stance within their practice. To obtain data for this project, connections with the local hospice care community were used to recruit interested individuals directly involved in service delivery through a convenience sampling method. Participant data was collected via a focus group with 9 participants, which was then recorded, transcribed, and analyzed. The method of analysis was thematic exploration and estimation of the prevalence of identified themes. Five major themes were identified through analyses: (a) individualized culture, (b) respect for others, (c) team-oriented approach, (d) implementation of cultural humility, (e) lack of formal training and integration of hands-on experience. Findings contribute to the generic hospice services knowledge base, working in synergy with previous research findings to help encourage future research studies on this topic.

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#### Dedication

"The role of culture is that it's the form through which we as a society reflect on who we are, where we've been, where we hope to be."

Wendell Pierce

I dedicate this project to אליזבת בודק, for continuing to honor the Jewish culture, hope, and tradition despite surviving the horrendous conditions of The Shoah (*Holocaust*) and liberation from Auschwitz. Your memory, narrative, and experiences serve as a living history that will never be forgotten. Thank you for instilling tradition, faith, and a passion for Judaism which continues to thrive today among your survivors.

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This project is the culmination of my experience as a student at Walden University's DSW Clinical Concentration program and my educational career, which I faced with encouragement, hardship, conviction, and frustration. While my name is the singular name on the cover of this project, there are a great many people without whom this project would not have been possible. Among those I want to thank are my family members, friends, colleagues, and various institutions that have contributed to this great achievement bestowing knowledge, advice, and support along the way.

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To my committee, Dr. Kristin V. Richards, Dr. Debora Rice, Dr. Nancy

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#### Section 1: Foundation of the Study and Literature Review

Social workers serve traditionally marginalized individuals, a group to which hospice patients belong (O'Mallon, 2009; Baah, Teitelman, & Riegel, 2018). Facing end-of-life issues, patients bring their traditions, beliefs, and values to the hospice arrangement, expecting that social service providers will fully respect them (Coolen, 2012). Cultural nuances color terminally ill patients' end-of-life experiences and guide their choices, yet the value systems of some cultures encourage minimal use of hospice care services or discourage careful advanced directive planning (Moore, 2015; Stein, G., Cagle, J. G., & Christ, G. H., 2017). Because of hospice patients' specific vulnerabilities, social workers often act as their advocates or as sources of additional support. While issues in the provision of culturally sensitive care within hospice exist, there remains limited recent research on these problems which presents a unique challenge in completing a relevant literature review but further asserts the appropriateness for this study as it contributes to the current body of burgeoning knowledge.

The traditional model of cultural competence serves as a useful foundation for developing practitioner knowledge of cultural awareness (Kleinman & Benson, 2006; Danso, 2016). Cultural competence offers a way to recognize cultural differences and to develop successful communications skills for interacting with various populations. Critics claim that this model erroneously sees cultural competence as static, with a final point of arrival where a practitioner ultimately becomes "competent" rather than seeing cultural competence as the result of a lifelong learning and training process achievable through constant self-introspection, education, and training (Tervalon & Murray-Garcia, 1998).

Despite the advancement of cultural competencies in social work and other helping professions, inequities of care remain, specifically related to the care of minority populations (Isaacson, 2014). Education and research platforms must stress the importance of cultural development, including self-critique in interactions with patients and advancing culture-specific training.

I suggest cultural humility as an alternative practice standard, as introduced and defined by Tervalon and Murray-Garcia (1998). As a concept, cultural humility asserts that cultural competence is a product of lifelong learning and development, whereby a practitioner participates in continuous self-reflection and introspection. It places particular emphasis on cultivating ongoing self-awareness and treats the client as an expert on his or her situation and experience (Fisher-Borne, Montana Cain, & Martin, 2015). Practitioners must minimize power imbalances in their relationship with patients and aim to unearth a vast network of cultural resources and strengths that may empower the client (Sheridan, Bennett, & Blome, 2013). Striving to learn about other cultures, traditions, and practices helps expand the practitioner's knowledge base (Tormala, Patel, Soukup, & Clarke, 2018). A shift in perception, as well as the implementation of practice, are fundamental here, with hospice social workers using the framework of cultural humility to guide practice interventions and resources utilized in the field.

This project will incorporate a qualitative research design and seek, through practitioner narrative analysis, to understand social work values as related to the concept of cultural humility which may identify ways to improve current cultural standards of practice in hospice care. Interviews with social workers focused on current practice

standards and the individualized ways such interventions implement culturally appropriate care daily for terminally ill patients. Culturally appropriate care is defined in this study as interventions and practice methods that consider cultural differences while meeting the specific needs of those served through a lens that focuses on bio-psychosocial-spiritual factors. Next, this research identifies, clarifies, and discusses relevant emergent themes concerning best practices in hospice care and potential errors with harmful effects for patients to be avoided. Section 1 addresses current diversity issues about hospice care personnel and patients along with associated demographic shifts. Common barriers to cultural diversity in hospice care are identified and explored, as are critical elements of both cultural competence and cultural humility, as well as how the concepts differ. Lastly, the section also provides an overview of cultural factors at the end of life and the social worker's role.

#### **Problem Statement**

Research indicates that culturally appropriate practices toward hospice patients dramatically improve the quality of existence at the end of life (Oguamanam, 2016). Current literature minimizes cultural humility as a concept, instead focusing on cultural competence and training among traditional medical professions in hospice settings (Moore, 2015). Cultural humility as a concept is just now beginning to gain momentum as a fundamental practice in social services and healthcare although it was initially introduced in the late 1990s (Tervalon, & Murray-Garcia, 1998). Cultural humility is the practice of challenging one's own beliefs, biases, and values continuously in the context of cultural development, education, and awareness (Yeager & Bauer-Wu, 2013). For

example, a social worker may self-identify as a Reform Jew, however, given the spectrum that Judaism operates under it would be inappropriate to assume similar customs or practices among an Orthodox Jewish patient or family. Because the concept of cultural humility is still evolving research is limited regarding its associated practice standards and overall effectiveness of the application in social services. The focus of this project is what current hospice social workers in Las Vegas, Nevada, identify as essential steps to enhancing cultural humility based on their subjective understanding of the concept and its appropriate application through culturally informed interventions within their practice setting.

Current cultural standards of practice developed approximately sixteen years ago, are generally the focus of the social work profession, through the educational and professional development of cultural awareness (NASW, 2015). The National Association of Social Workers' Code of Ethics (2018) supports the continued development of cultural humility in place of competency-based standards (*cf. standard 1.05*) with a focus towards the culture, tradition, and values of those served. Social workers can benefit from ongoing education in death and dying practices and cultural standards of bereavement, both normative and complicated, because the experiences of grief, dying, and mourning vary significantly among and between cultures (Brandsen, 2005; Shear, Simon et. al, 2011; Metlzer, 2017). Even so, many social work education programs continue to neglect to provide their graduates and future practitioners with training in end-of-life care (Turner, Kuyini, Agustine, & Hunter, 2015). For example, one study conducted descriptive analyses of over 700 textbooks used in graduate-level social

work education and found that only 3% of all of the texts pertained to specific practice situations or offered education related to end-of-life care (Kramer, Hovland-Scafe, & Pacourek, 2003). Another study reviewed end-of-life care as a specialization for social workers and examined how one CSWE-accredited program implemented education based on this vulnerable population (Murty, Sanders, & Stensland, 2015). The study concluded that, while training is growing overall, a greater need exists to continue developing such a practice training to ensure that practitioners are knowledgeable. Through the development of cultural humility as a concept, value, and practice a social worker can meet ethical standards of the profession while serving the best needs of the patient by recognizing how culture impacts the bio-psycho-social-spiritual stressors a patient faces at the end of life.

Social workers have a vital role in resource identification, grief and bereavement support, and assistance with final arrangement planning. Due to the professional value of self-determination as an ethical concept, social workers emphasize strengths and empowerment perspectives to improve the quality of life of a terminally ill individual through helping them remain independent for as long as possible (Hobart, 2002; McCormick, A. J., 2011). The interdisciplinary team receives support from social workers in recognizing the complex needs of the patient and psycho-social stressors while maintaining collaborative relationships. Since social workers are instrumental in the provision of services at the end of life, they must have an in-depth understanding of evidenced-based cultural practices and a familiarity with how to enhance and develop cultural humility among hospice practice settings (Chang, Simon, & Dong, 2012). As it

stands, there are efforts to implement education and training programs to provide foundational knowledge for cultural diversity and awareness throughout social work as a profession (Rosen, 2017). Practitioners have a responsibility to focus on cultural practices, traditions, and beliefs established throughout their career development to ultimately strengthen the social worker-patient relationship while complying with the profession's pillar ethical principles.

#### **Purpose Statement**

The goal of this research study is examination of social workers' knowledge in working with terminally ill patients among hospice settings to discover how practitioners employ cultural humility practices for enhancing the end-of-life experiences in such settings while respecting individual differences and recognizing cultural nuances.

#### **Research Question(s)**

- 1. How do social workers in Nevada define cultural humility in the context of hospice social work practice?
- 2. What values or principles do hospice social workers in Nevada consider most important in providing culturally appropriate care to hospice patients?
- **3.** In what ways have hospice social workers in Nevada implemented a cultural humility stance within their practice?

#### **Key Terms**

Advance directive – a statement that describes an individual's wishes regarding specific medical treatment if they become unable to verbalize their desires (O'Sullivan, Mailo, Angeles, & Agarwal, 2015).

Aggressive treatment – when a terminally ill patient chooses to continue with diagnostic exams, curative treatments and is not presently seeking comfort level of care (Richardson, Sullivan, Hill, & Yu, 2007).

Bio-psycho-social-spiritual assessment – an assessment tool that takes into account the patient's biological (basic needs), psychological (cognition, identity, and self-concept), social (support system and community), and spiritual factors (sense of self, purpose, or meaning) to formulate a comprehensive clinical impression (Singer, 2007).

Cardiopulmonary resuscitation (CPR) – a medical procedure performed by sustained compression of the chest, used to restore blood flow to a patient's heart, thus restarting it and enabling the patient to breathe again (Sehatzdeh, 2014).

Collectivism – a cultural orientation that places great significance on the group, family or the community over the individual (Kuo, 2013).

Coordination of care – organizing patient care between professionals, including the patient, to facilitate appropriate service delivery and continuity of care (Mason, B., Epiphaniou, E., et al., 2013).

Cultural competence – a set of behaviors, attitudes, policies, and standards that enable social workers to collaborate with people of differing racioethnic backgrounds (Micek, 2014).

Cultural humility – a lifelong evaluation and exploration of self and a commitment to develop an understanding of and respect for diverse communities, groups, and individuals (Fisher-Borne, Montana Cain, & Martin, 2015).

Culturally appropriate care - interventions and practice methods that consider cultural differences while meeting the specific needs of those served through a lens that focuses on bio-psycho-social-spiritual factors (Given, Sherwood, & Given, 2008).

Culture – a set of learned beliefs, traditions, values, behaviors, and customs of a specific group or society (Mehotra & Wagner, 2009).

Do not resuscitate order (DNR) – a medical order typically written by a doctor instructing healthcare providers not to complete cardiopulmonary resuscitation in the event a patient stops breathing or his or her heart ceases to beat (Cook et al., 2017).

Durable power of attorney for healthcare (DPOA) – a document that goes into effect when a patient is incapacitated or unable to make decisions for himself or herself, allowing another individual to act on that patient's behalf (Miller, 2016).

Ethnogeriatrics – the intersection of ethnicity, culture, and aging about specific cultural practice, tradition, and heritage (Crewe, 2004).

Ethnogeronotology – the study of aging groups about national origin, cultural tradition, and practice concerning race (Barresi, 1990).

Full code – the opposite of a DNR order, an order indicating a patient wants all life-sustaining measures or treatments possible in the event his or her heart should stop (Ankuda, Fonger, & O'Neil, 2018).

Healthcare proxy (HCP) – a legal document whereby a patient designates an individual to make healthcare decisions on their behalf in the event they become incapacitated or unable to make healthcare decisions for themselves (Thompson, 2015).

Hospice - a philosophy and specialized level of care for a person who has been determined by a doctor to have a qualifying diagnosis including prognosis of six months or less of life (American Academy of Hospice and Palliative Medicine Frequently Asked Questions about Hospice and Palliative Care, 2015)

Individualism – a concept that emphasizes autonomy and where the interests of the individual viewed as more critical than those of the community, directly contrasting with the concept of collectivism and is more visible in Western culture (Yun, Mohan, & Zhao, 2017).

The Interdisciplinary Team (IDT) – a coordinated group of professionals that comprise the patient care team, typically the IDT meets once a week to discuss patient cases (Moore, Bastian, & Apenteng, 2015).

Intersectionality - the confluence of religion, race, gender, and sexual orientation that ultimately applies to an individual creating intersecting systems of potential disadvantage (Mattesson, 2014).

Living will – a document that makes an individual's wishes known; it differs from a POA as it does not designate a person to act on behalf of those wishes (Chehuen et al., 2015).

Palliative care – an approach to care that seeks improvement in the quality of life by alleviation of pain and emotional stressors (Al-Mahrezi & Al-Mandhari, 2016).

#### **Nature of Doctoral Project**

A classic qualitative design is the methodology used to recognize how social workers define and implement cultural humility when working with terminally ill

patients. Using a basic qualitative approach will assist in gaining an understanding of practitioner attitudes, beliefs, values, and opinions about cultural humility in their practice setting and allow for expression of their feelings as related to this concept (Percy, Kostere, & Kostere, 2015). These insights may benefit the literature by identifying essential gaps in the social workers' knowledge and comprehension of cultural humility as a useful framework to offer culturally appropriate care at the end of life

A focus group was conducted with nine community-based hospice social workers currently employed in a hospice setting which served to identify emergent themes. Essential to developing an understanding of how to improve the end-of-life experiences of patients; is a semi-structured focus group concentrating on areas where cultural practice opportunities for improvement may exist. This focus group provides insight into practitioner development of cultural awareness, agency-specific standards, and how practitioners feel their views of cultural humility impact the terminally ill patient.

Practitioners also clarified current company policies in place regarding culture or diversity and how these concepts impact end-of-life care. Emergent themes from interviews allow me to address the study's research questions more thoroughly.

I utilized personal connections within the Las Vegas community as a former hospice social worker to gain access to potential participants. Recruitment of potential participants' occurred through general outreach through telephoning local hospice organizations inquiring about interested participants using a convenience sampling method. Once recruited, interested participants received information synthesizing the

purpose of the project and expectations of contribution. I offered material regarding informed consent, confidentiality, and other relevant topics to augment participant understanding before their participation. Lastly, before data collection began, I educated potential participants on the purpose of the project, benefits of participation, and any prospective risks anticipated with their involvement.

#### Significance of Study

The findings of this study may assist professional social workers in hospice or palliative care through a contribution to the body of knowledge about the implementation of practice methods grounded in cultural humility. Through insights gained within the scope of this study, potential standardized measures of cultural practice may be developed which could support practitioners in providing the best possible care to their patients, with the potential to significantly affect a terminally ill patient's quality of life. Some studies indicate that, due to various cultural nuances, some minority groups are less likely "buy-in" to the hospice philosophy which usually creates an institutionalized barrier against end-of-life care (Burrs, Greene, & Reese, 2006; Frey, Gott, Raphael et. al, 2013). By identifying essential gaps in social workers' knowledge, this study may assist in enhancing cultural humility practices and aid in the development of education for practitioners from a cultural standpoint.

Hospice uses a family-centered approach with the assistance of professionals, volunteers, and family members involved in the holistic care of a terminal patient (Kobayashi, 2016). Social workers are dynamic members of the interdisciplinary support team assisting with grief counseling, in final-arrangements preparation, and linking

patients to various community resources (O'Connor & Fisher, 2011). Through these actions, social workers offer empathy and support, and bring a specific emphasis on patients' resources, including strengths to provide comfort and foster independence even during the end-of-life transition. Social workers, moreover, maintain collaborative relationships with members of the interdisciplinary team to identify psychosocial needs, stressors, and challenges facing the terminally ill patient. Teamwork is fundamental at this level of care as each professional adds information to case formulation, creating a more comprehensive method of patient care.

Improvement of practitioner knowledge on cultural humility and end-of-life practices overall is the goal of the study, which may allow hospice social workers to be better informed about and empathetic to various cultural issues that manifest during hospice care. Social workers are involved in the provision of end-of-life care services; therefore; it is anticipated that the findings from this study may aid in planning and implementation of effective hospice care social work interventions which may further empower dying patients, encouraging understanding of their cultural identities and traditions at their end-of-life. Findings from this study may also contribute to the field of social work beyond hospice care, as cultural humility is a practice that may expand among various other agencies such as working with children and family services, forensic settings, or even in direct clinical practice.

#### **Conceptual Framework**

Cultural diversity is becoming a more complex concept and an emphasis on educational programs in the social sciences wherein graduates work with diverse

individuals and minority populations regularly (Reyes, Hadley, & Davenport, 2013). Cultural humility offers an enhanced alternative to cultural competence by highlighting the clinician's need for contemplation, introspection, and critical evaluation of self (Alsharif, 2012). Development of cultural awareness is essential as it allows for interpersonal and professional growth through augmented understanding. Becoming aware of personal biases or predetermined notions is beneficial in appreciating different values, worldviews, and cultures (Tervalon & Murray-Garcia, 1998). Rather than practitioners having the goal of achieving proficiency in understanding diversity and difference, they would find more value in educating and encouraging the ongoing professional and personal development of cultural humility.

Cultural humility is the conceptual framework for this project, offering insight into practices that evidence culturally focused care through social work interventions in hospice settings. Contrary to cultural competence, cultural humility involves recognition of one's experiences and self-evaluation, mainly developing as a process-oriented approach rather than one rooted in education (Yeager & Bauer-Wu, 2013). Becoming self-aware is a meaningful indication of culturally humbled practice in which an individual surrenders to the process while remaining secure in his or her experience and belief systems. As a proactive process, cultural humility engages professionals through increasing consciousness of others' experiences, habits, and values (Fahlberg, Foronda, & Baptiste, 2016). An example of cultural humility would be a practitioner seeking to develop an understanding of a patient that has unfamiliar traditions or beliefs and

engaging in a strengths-based dialogue with the patient to increase awareness of their practices.

Because cultural humility is relatively new and somewhat-ambiguously defined concept, practitioners must complete research to develop familiarity with differences and improve understanding of intersectionality (Epner & Baile, 2012). *Intersectionality* is the confluence of religion, race, gender, and sexual orientation that ultimately applies to an individual creating intersecting systems of potential disadvantage (Mattesson, 2014). Intersectionality as a concept assists in understanding cultural humility practices by identifying areas where systems of difference converge, interconnect, or overlap. Discrimination has various threats, as evidenced in the concept of intersectionality, whereby an individual belongs to multiple minority or vulnerable categories. An example is a single African American female in hospice care, who also identifies as a lesbian. This woman may face possible barriers due to belonging to various groups of potential disadvantage, possibly facing homophobia, racism, or misogyny due to possible ignorance surrounding these minority statuses.

Several pillar values are beneficial to understanding this project, including social justice, dignity, and worth of the person, the importance of human relationships, and competence. Social work as a profession emphasizes identification of social problems and advocacy for patients facing such difficulties. In this project, the concept of cultural humility is the foundation used to address the issue of culturally appropriate care for those in a hospice setting.

#### Values and Ethics

Various ethical responsibilities from the NASW Code of Ethics additionally relate to this project, including standards 1.02, 1.04, and 1.05, relating to how the social worker engages with the client, competence of practice, and the search for additional information and knowledge to enhance cultural diversity. These professional values may be used to advocate on behalf of those unable to do so for themselves, which is often the case in hospice social work, allowing the patient the right to self-determination, and social workers additionally must practice competently within their scope.

Social workers often work with underserved populations, including those that are within the scope of hospice care. Because terminally ill individuals are struggling with various stressors including role change or conflict, their mortality, and being critically ill, their values and beliefs about various dynamics become relevant. Such personal issues can be challenging to navigate or understand without the use of continued education, dialogue, and introspection on the part of the social worker. Cultural humility encourages self-reflection and lifelong learning to encourage more sensitivity among practitioners. The current study examined how social workers first and foremost define and comprehend cultural humility while also inquiring what principles social workers in Las Vegas, Nevada find as most relevant in the implementation of culturally sensitive care with hospice patients.

#### **Review of Professional and Academic Literature**

Review of the professional and academic literature includes previous applicable research, which informs the current project, relevant questions, and the purposes of this

study. Research findings served as guidelines to develop the thematically based literature review identified in this chapter. This section will build upon results from relevant research in the field of study and will highlight strengths, limitations, and gaps in the literature. ProQuest, PsychInfo, JSTOR, PubMed, and Academic Search Complete, accessible through the Walden University library services, provided sources for articles relevant to this project. Furthermore, an extensive hand search of several popular journals that focus on bereavement, hospice philosophy, and palliative care practices was conducted to be as comprehensive as possible. The initial search encompassed journal articles that were scholarly and peer-reviewed, published within the last ten years, and with full text, using the terms hospice, social work, intersectionality, cultural humility, diversity practices, end of life, and social work. However, due to the limited current research on this topic in particular, the search was expanded from ten to fifteen years to provide a thorough review of relevant literature. It is my understanding that this limitation in scholarship only serves to strengthen the need for research in this arena and projects such as this.

#### **Diversity in Society and Demographic Shifts**

Comprehending demographic shifts in society is vital, as these transferences in the population have led to increased diversity, especially at the end of life and throughout the maturation process overall. Whereas historically, most people prefer to expire in the comfort of their own home, the trend of people living longer significantly limits the practicality of an in-home death and requires exploration of options for hospice care (Kaiseth & Theisen, 2017). Previously, a significant need to seek additional support in

caring for a terminal patient did not exist. However, given the changes in current demographics, as people are generally living longer and acquiring more complex conditions, hospice care is now increasingly in demand (Landers et al., 2016).

A recent pioneer study conducted in England and Wales looked at the growing need for palliative and end-of-life care services with projections until the year 2040 (Etkind et al., 2017). Findings indicated that the need for end-of-life care will grow exponentially due to longevity in lifespan and increased chronic conditions, though from their research it remains unclear how professionals are expected to meet these growing needs (Etkind et al., 2017). Limitations of this study include that the populations of England and Wales differ significantly from that of the United States and that researchers relied heavily on accurate death certificates to make their projections. Despite these limitations, the study has relevance in the conversation regarding demographic shifts, greying populations, and how professional practice must adjust in light of these changing statistics.

In the last decade, the American and global population has become more diverse based on location, identity, sexual orientation, socioeconomic status, cultural identification, religion, and various other factors. (Johnson & Parnell, 2016). These changes in demographics are creating a unique society while raising awareness of the specific cultural and traditional needs of minority populations. Culture can impact the way one views or experiences death; for example, Elizabeth Kübler-Ross, a well-known psychiatrist and creator of the stages-of-grief model, famously viewed death as a conclusion of life and something positive rather than an event to be feared (Kubler-Ross,

1975). She was even quoted as saying, "I've told my children that when I die, to release balloons in the sky to celebrate that I graduated. For me, death is a graduation." Because there is so much variation in cultural interpretations of illness, bereavement, and dying, social workers must develop a comprehensive understanding of such distinctions and how these differences can ultimately impact healthcare delivery.

Minority groups traditionally underutilize hospice care for a various reasons, including an overall lack of familiarity with the hospice philosophy, African Americans' distrust of the medical system, and an instilled value of collectivism among Latino/a, indigenous, and Asian communities (Rhodes, 2006; Quinones-Gonzalez, S., 2013; Dillon, P. J. & Basu, A., 2016). Hospice's philosophy encourages compassion at the end of life using a team-oriented approach to restore dignity and build patient resources. One study found that Caucasian participants were 71% more likely than African American equivalents to utilize hospice services among 31 of 40 states included in the sample (Connor, Elwert, Spence, & Christakis, 2008). In their exploratory study, the researchers calculated a hospice utilization ratio using data obtained through the Center for Disease Control death certificate records to examine differences in hospice utilization by race. Of note is that hospice utilization rates in the study were population level quantities rather than sample estimates and statistical tests were not reported in the publication. Although their project has some limitations—namely, that it includes only data from Caucasian and African American participants, the study remains relevant today, as many minority groups use hospice only as a last resort, and literature denotes that many hospice patients are unfamiliar with the services provided by hospice and have no concept of its ethos

(Cagle et al., 2014). Such cultural nuances are the springboard for this research, and while there is overall a greater utilization of hospice services by mere demand, many minority groups continue to struggle with their cultural obligation when a loved one chooses hospice care.

According to the National Hospice and Palliative Care Organization (NHPCO) as of 2016, approximately 85% of all hospice patients nationally were Caucasian, 8% were African American, 2% were Hispanic, and 1% were Asian (NHPCO, 2017). These numbers imply demographic shifts are already beginning to create a change in those that are pursuing and utilizing hospice services at a national level. The NHPCO has recently begun a "diversity initiative" which includes outreach guides to specific underrepresented minority groups encouraging providers to seek additional training on cultural issues and implore sensitivity when working with minority populations (NHPCO, 2019). According to research conducted as of 2013, less than one-fifth of all hospice patients nationally belonged to minority groups (Campbell, Baernholdt, Yan, Hinton, & Lewis, 2013). NHPCO has therefore delegated a Diversity Advisory Council that researches various hospice affiliates to ensure that outreach to minority groups and underserved populations continues to grow (NHPCO, 2019). Further, hospice organizations and NHPCO affiliates may review materials provided through the annual NHPCO conference, online webinar, training series, and provider-specific resources via the NHPCO website under the diversity initiative tab.

Current estimates indicate by 2040 the populace in the United States will radically shift from a homogenous society to a heterogeneous structure, a change due mainly to the

maturing of the Baby Boomer generation and the fact that older adults, in general, are now living longer (Johnson Jr. & Parnell, 2016–2018). Ethnogeriatrics (also called *minority aging*) is an emerging subfield of gerontology focusing on the aging of population groups that belong to different cultures, traditions, and heritages (Solle & Harrell, 2013). Ethnogerontologists predict by 2055 there will no longer be a single racioethnic majority in the United States; instead, a shift will take place toward a minority-majority (see figure below as adapted from Pew Research Center; Pew Research Center, 2015). In response to these changing demographics and the diversifying profile of those seeking hospice services, a pressing need exists for increased knowledge, cognizance, and understanding among practitioners to develop a skill set in cultural humility to address this multicultural societal shift (Campinha-Bacote, 2019).

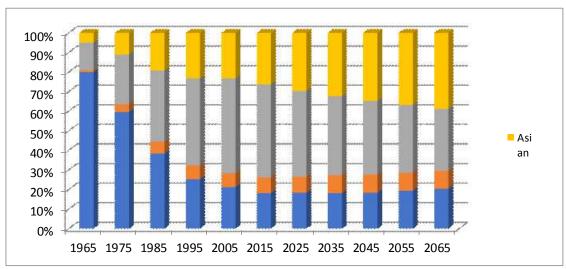


Figure 1: Pew Research Center Projections 2025–2065

Source: Pew Research Center estimates for 1965-2015 based on adjusted census data; Pew Research Center projections for 2025-2065.

## **Historical Development of Culturally Competent Practice**

Education and training in diversity and cultural awareness have been hallmark focuses of the National Association for Social Workers (NASW) and the Council for Social Work Education (CSWE) to improve outcomes among professional social workers both in education and CEU training (Faruque & Ahmmed, 2013). Social work competencies foster development by creating a need for additional education on race, ethnicity, sexual orientation, spirituality, and religious affiliation assisting in developing knowledge among various cultural nuances. Shifts in focus highlight the need for social workers to understand cultural distinctions, traditions, and specific normative grief reactions or bereavement practices (Kleinman, Eisenberg, & Good, 1978; Wallace, Thielman, Cimino, & Rueda, 2017; Cait, 2017). Historically, diversity and understanding of the concept of cultural humility was discretionary in social work education, and while the profession seeks to embrace those that are different, the mandates for cultural training in CSWE-accredited Bachelor of Social Work and Master of Social Work programs have been in place only since the early 1990s (Kohli, Huber, & Faul, 2010).

Significant changes have occurred over time among the structure of culturally based training; for example, in the 1950s and 1960s, there was an emphasis on minority groups assimilating into the broader context of society (Smith, 1985; Pernell-Arnold, Finley, Sands, Bourjolly, & Stanhope, 2012). The implicit structure encouraged dominant perspectives of the era with little attention to respecting, understanding, and celebrating differences. During the late 1960s and in the early 1970s a shift began, whereby minority groups, including women, fought for their narratives to be heard, placing pressure on

curricula and encouraging sensitivity to specific cultural problems (Sowers-Hoag & Sandu-Beckler, 1996; Pernell-Arnold, Finley, Sands, Bourjolly, & Stanhope, 2012). In the 1980s and 1990s a dramatic shift occurred, from ignoring the needs of minority groups to celebrating differences and broadening teaching from just gender and race to include additional issues of religious affiliation and sexual orientation (Garcia & Van Soest, 2000). Prevailing cultural standards became questioned regularly, and cultural pluralism began to allow a focus on specific cultural nuances by placing pressure on universities to teach to the changing times (Jani, 2014). During this period, CSWE began reflecting inward to foster lasting policy changes seeking to address ethnocultural frameworks to become inclusive of differences, whether they be cultural, religious, or ethnoracial (CSWE, 2015).

# **Cultural Competence in Social Work Practice**

Previously, in the NASW Code of Ethics (2008), the ethical standard 1.05 was titled Cultural Competence and Social Diversity, emphasizing developing knowledge in cultural differences, recognizing the role culture plays in social work services and encouraging practitioners to continue education related to cultural development.

However, as of 2018, the NASW has revised the profession's code of ethics, removing the word "competence" from this standard. Further changes to ethical practice as related to culture include the addition of a competency related to awareness of socioeconomic disadvantage and the role it plays in the use of technology.

The NASW Code of Ethics (2018) identifies the following standard for cultural practice as a social worker's ethical responsibility to clients:

- 1.05 Cultural Awareness and Social Diversity
- (a) Social workers should understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures.
- (b) Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups.
- (c) Social workers should obtain education about and seek to understand the nature of social diversity and oppression with respect to race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, and mental or physical ability.
- (d) Social workers who provide electronic social work services should be aware of cultural and socioeconomic differences among clients and how they may use electronic technology. Social workers should assess cultural, environmental, economic, mental or physical ability, linguistic, and other issues that may affect the delivery or use of these services.

Understanding these obligations entrusted to social workers through the NASW professional code is crucial in recognizing the benefit to culturally sensitive practice, especially for those patients in hospice. The Code of Ethics stresses awareness of self, continued development of cultural training, and recognition of how difference or disadvantage may impact the social work alliance with a patient. Therefore, it can be inferred that the NASW Code of Ethics supports the continued growth of cultural humility in practice in lieu of previous models of competence.

Cultural competence is the foundation of social work practice, though this concept is changing to meet the needs of the diverse population as evidenced by the NASW's Standards for Cultural Competence in Social Work Practice (2015), which places considerable emphasis on the developing concept of cultural humility. Cultural competence is a tool to enhance knowledge of special populations and minority groups, maintaining a level of sensitivity to diversity issues and recognizing a "one size fits all" approach does not exist (Alegria, Atkins, Farmer, Slaton, & Stelk, 2010). Culture is a multifaceted concept which evolves regularly as individuals often have their definitions. Essentially, cultural competence is an umbrella term for the knowledge, skills, and resources that social workers use to engage clients of various cultural backgrounds. In social work practice, this method involves supporting patients through interventions, respecting patients and their experiences, and affirming patient value systems. Utilizing cultural competence allows social workers to employ cross-cultural skills to work effectively with people from many backgrounds by acting as an advocate, broker, and case manager among other roles.

# **Strengths and Limitations of Cultural Competence**

Cultural competence is closely linked to cultural diversity, as the model was created from a recognized need to develop a baseline understanding of those that are marginalized or belong to a minority category (Jongen, McCalman, Bainbridge, & Clifford, 2018). As a concept, cultural competence has garnered much attention as it emphasizes the interpretation of racioethnic dynamics in the helping relationship and encourages respect through mutual understanding (Kataoka-Yahiro, McFarlane, &

Koijane, 2016). Cultural assessment is also a hallmark of this method, whereby a practitioner recognizes nonverbal communication patterns, linguistic differences, and interprets information provided from the patient (Doorenbos & Schim, 2004; Rine, C., 2018). Flexibility in professional development is essential here as this concept adapts to various settings seeking to decrease disparities while including those that identify as "other"

Cultural competence, however, views learning as finite with a secure connection to education and training but with a limited emphasis on cultural awareness as a lifelong learning process (Kumagai & Lypson, 2009; Kohli, H., Huber, R., & Faul, A., 2010).

Once a person completes training or education on cultural topics, the implication of this model, though not explicitly stated, is that he or she has proficiency. Because education and training most often come from secondary sources, general knowledge of cultural nuances may lend itself to be overgeneralized or even stereotypical if not challenged by the social worker (Nadan, 2017). Due to the attention placed on the "other," it is inferred that the tendency is to focus on learning about difference rather than emphasizing oneself. Lastly, cultural competence does not focus as closely on critical self-reflection and the tenets of intersectionality as they relate to social work practice (Malat, 2013).

Practitioners' thoughtful reflection allows for review of personal biases, preconceived notions, and awareness of the perspectives of others as related to these social constructs.

#### **Cultural Humility Building upon Cultural Competence**

Early conceptualizations of cultural competence evolved from concepts in social science and health care as a response to marginalized communities (Kwame, 2008;

Alvarez-Hernandez, L. R. & Choi, Y. J., 2017). Cultural competence has several foundational pillars, including the elaboration of a fundamental knowledge base, and the need for a social worker to be aware of personal beliefs and values while they hone their professional skills (Saha, Beach, & Cooper, 2010). The process of cultural training within the social work profession developed from an acknowledged demand to improve and cultivate an understanding of those who are different and to recognize how unique perspectives can be a source of strength and resiliency among individuals, especially at the end of life (Carpenter, 2016). Cultural competence is a mandatory skill in various educational programs, such that schools often require diversity-recognition courses, either as electives or graduation-specific requirements (Gallegos, Tindall, & Gallegos, 2008; Jani, J. S., Pierce, D., Ortiz, L. & Snowbel, L., 2011). Cultural competence is a springboard for the concept of cultural humility, which is a natural progression from a recognition that the inherent nature of competence did not meet the needs of diverse populations.

Critical in hospice care is the concept of cultural humility, as many times patients are unaware of their sources of support, strength, and resilience or how culture impacts their end-of-life experiences (Wakefield, Bayly, & Seiman, 2018). The methodology of cultural humility augments the general theoretical foundation of cultural competence by expanding upon required knowledge and practices (Furlong, 2011). Professional social workers are encouraged to move away from the idea of "competence" and toward a greater lifelong learning experience via cultural humility, built upon the pillar axioms of the cultural competence model.

Melanie Tervalon (2012), a founder of the concept, described cultural humility in the documentary *Cultural humility: People, principles, and practices* as a method whereby one "maintain[s] a willingness to suspend what [they] know, or what [they] think [they] know, about a person based on generalizations about their culture." While scholars have recently honed their focus on the concept of cultural humility and also expounded its analysis, cultural competence still has a place in social work practice. Research from this project builds upon current literature, recognizing the underpinnings of cultural competence while encouraging enhanced cultural awareness and interventions specifically within hospice settings.

To be successful in implementing cultural humility a practitioner should consider that they may never be fully proficient in any experience or culture (Renzaho, Romios, Crock, & Sonderlund, 2013). The concept of cultural humility is appealing because it encourages the social worker's continued efforts in learning. For increased cultural awareness and understanding of diverse patients, a social worker must accept that many perceptions, customs, and cultural nuances exist and that such experiences may never be fully understood (American Hospital Association, 2013). This process is always changing and developing while promoting professional respect for "the other" through the emphasis on ongoing education and critical self-reflection (Chang, Simon, & Dong, 2012). Hospice social workers must learn early on in their professional development to become comfortable with the evolving process of cultural-awareness training, as it will strengthen practice interventions and interactions with patients served (Jongen, McCalman, & Bainbridge, 2018). Additionally, where possible, professionals must seek

out opportunities to develop personally and professionally, whether through work-related training, continued education, or specialized conferences.

**Elements of Cultural Humility.** Cultural humility is the process whereby one moves away from personal conceptualizations of culture, tradition, or racioethnic identification, and allows for continued learning from the experience of patients (Cleaver, Carvajal, & Sheppard, 2016). Cultural humility offers multiple dimensions of enhanced cultural awareness, including lifelong learning with a specific focus on critical introspective reflection, recognizing power imbalances between the patient and his or her environment, and encouraging accountability on the micro-, mezzo-, and macro-levels (Chang, Simon, & Dong, 2012). Fundamentally, cultural humility involves creating a deeper meaning for the individual perspective with consideration for the personal experience by allowing the patient to share his or her narrative and, through this process, increases the social worker's cultural knowledge base (Hook, 2015). As a reflective process of awareness of self, personal biases, and historical experience, cultural humility allows a social worker to build upon professional knowledge to offer successful and effective practices while recognizing potential imbalances in power or how culture impacts end-of-life care.

Importance of Cultural Humility. Approaching cultural awareness in this manner is essential, as it allows an appreciation of one's own culture and fosters acceptance of others. Culture is a relatively new but well-developed concept; though, within the last four decades, literature has focused on theoretical tenets that may increase competency within the profession of social work (Sousa, 2016). The current project seeks

to understand social worker perceptions, values, and understanding of cultural humility as a concept as well as how this concept potentially impacts practice interventions or interactions with terminally ill patients. Of particular focus within the lens of cultural humility is the aspect of introspection and how such self-reflection impacts care.

Social workers must be aware of specific cultural nuances, especially at a patient's end of life, as various traditions are culture-specific and can prominently improve the quality of a patient's life during the poignant and challenging period of hospice care (Waldrop, 2011). Instances of culture and diversity are recognizable in all interactions, making the concept of cultural humility vital to embrace those that are different. For example, a hospice social worker may encounter someone that is of indigenous origin and may also be unfamiliar with culture-specific traditions and practices at the end of life. In this situation, the social worker should acknowledge their deficit in knowledge of this population, asking open-ended questions and using the skills of clarification or reflection to explore what is most important to the individual and his or her family during this emotional time.

Cultural humility advocates for acknowledging our own biases and experiences but also encourages practitioners to be willing to grow professionally by promoting learning about and understanding other cultures in-depth (Lopez, 2007; Sloane, H. M., Daivd, K., Davies, J., Stamper, D., & Woodward, S., 2018). Various dynamics are involved in cultural knowledge, and this is not unique to the concept of cultural humility but rather an overarching theme in the grander theoretical basis of culture as a concept. The purpose of developing and expanding knowledge includes creating a more

comfortable experience for a terminally ill patient while also starting where the patient is to enhance their resources and develop strengths (Metcalf, 2013). Fundamentally, the concept of cultural humility allows a practitioner to reject the role of expert to develop instead an authentic curiosity for the patient experience recognizing how differences impact end-of-life care.

#### **Cultural Factors at the End of Life**

Currently, racioethnic minority groups constitute one in three of all individuals in the United States, and these numbers are expected to grow to become the majority-minority (Searight & Gafford, 2005). Cultural influences meaningfully affect the application of end-of-life healthcare services and decision-making processes among family members for many personal, cultural, and familial reasons. Various concepts apply to the setting of hospice and palliative care, such as individualistic versus collectivistic tendencies, personal definitions of family, and the general communication patterns utilized in specific cultures (Steinberg, 2011). For example, among more individualistic communities it is often considered appropriate to place a patient in a long-term care facility or a skilled nursing facility, whereas among more collectivistic communities, conversations regarding higher levels of care are overlooked, with help requested once problems have become severe.

Increasingly relevant at the end of life are personal definitions of the family, which may include the interpretations of gender roles, who acts as a caretaker for elders, and who constitutes the "nuclear family," with some cultures embracing extended family members (Broom & Kirby, 2013). In the hospice setting, tensions are often high as

people typically are either in pre-bereavement or experiencing loss as the patient's illness progresses. Many cultures recognize kinship ties as valid family connections and value opinions from all who contribute; this is especially relevant among those of African American descent as this group tends to have extended family support (Stewart, 2007). Social workers in a hospice setting should be aware of the specific communication patterns of diverse racioethnic groups—for example, how Hispanic patients often seek the advice of professionals and use this expertise to clarify their own decisions, whereas African Americans are primarily distrustful of medical systems of care (Evans Winter & Cowie, 2009). At times conflict emerges toward the end of life, ultimately the result of poor communication and minimal preparation among the family circle, including avoidance of advance directive planning or, as in some cultures, males speaking for females within the family. For social workers to best serve in hospice, cultural nuances, definitions of family, and appropriate interactions among family members must be understood, as this serves to improve cultural practice in hospice care.

Barriers to Cultural Diversity in Hospice Care. Hospice is a philosophy and a specialized level of care for a person who has been determined by a doctor to have a qualifying diagnosis including prognosis of no more than six months of life (American Academy of Hospice and Palliative Medicine Frequently Asked Questions about Hospice and Palliative Care, 2015). Hospice alleviates symptoms of pain, provides immediate care to an individual, and has a patient-centered approach to care. An individual must be regularly recertified based on symptoms, and prognosis; while a patient enters hospice expecting to die within six months, many individuals have recertification periods that last

throughout many months or even up to a year (Rahman, 2017). Average lengths of stay in hospice, however, are about 21 days, with shorter admission being a matter of hours or a few days (Waldrop & Meeker, 2012). Studies on the length of stay in hospice settings also indicate a need to provide further education to patients and families regarding hospice services, as many only seek out services as a last resort.

Many patients and families are unfamiliar with when to seek hospice care, hospice services provided, and with differences between hospice and palliative care. Similar to hospice, palliative care has an interdisciplinary approach; conversely, the primary focus of this level of care is to provide relief for pain, whether physical, psychological, or emotional (Rome, Luminais, Bourgeois, & Blais, 2011). Those admitted to palliative care also have a life-limiting illness, though unlike in hospice care they may continue curative treatments (Rome, Luminais, Bourgeois, & Blais, 2011). Palliative care has a different funding source than hospice, and services are rendered in the home or hospital settings whereas hospice is provided within a patient's dwelling (including personal residence, assisted living facility, or skilled nursing facility), unless a patient's death is imminent and he or she goes to an inpatient facility to expire (Ellershaw, 2003). Sampson, Finlay, Byrne, Snow, and Nelson (2014) conducted a study using thematic analysis to explore the meaning that patients and caretakers place upon palliative care services, emphasizing personal experiences. Their sample was approximately 594 anonymous text-based responses from both caregivers and patients documenting personal experience with palliative care services. The findings of their study indicate that emotional experience is essential to understanding how best to care for

palliative patients. Most interesting in their results, which relates to the premise of the current study, Sampson et al. (2014) discovered that the emotional experience of caregiving was especially relevant to outcomes, based upon their definitions this included "respect, renewal, refuge, and restorative care" which is closely linked to cultural affiliation (Sampson, Finlay, Byrne, Snow, & Nelson, 2014, p. 293). According to their study, patients seek autonomy while also being involved in communications regarding their illness, a concept that translates well to hospice patient satisfaction.

Barriers to hospice care are multifaceted and ultimately relate to lack of knowledge regarding the purpose of this level of care, services offered, or personal value systems. Accepting and recognizing the need for hospice care raises emotions for many, regardless of status as patient, family, or friend. Research indicates that views of hospice are generally negative and are related only to death and dying processes (Broom & Kirby, 2013). A study conducted in 2016 focused on perceptions of hospice care and knowledge about services; it found that many people included in the sample were unaware of differences between hospice and palliative care, ultimately viewing both as "negative and scary" or synonymous with death (Slomka, Prince-Paul, Webel, & Daly, 2016). Slomka et al. (2016) conducted four focus groups in spring 2013 to obtain information regarding participant understanding of palliative care as a concept, palliative care as differing or related to hospice care, and potential associations with the dying process. The researchers utilized a sample of n = 22, with each focus group consisting of 5 to 7 participants and lasting approximately 90 minutes. Their results indicated that most participants viewed palliative care as preparation for death, improvement of the quality of life, and a general

unfamiliarity with the concept overall (with answers such as "What is the definition?") (Slomka, Prince-Paul, Webel, & Daly, 2016, p. 479). While it is true that hospice care is for those considered terminally ill, with no requirement that a person must be imminently dying, no expiration date exists for those admitted to this level of care. However, palliative care is generally a step before hospice admission and includes comfort care measures where patients may still seek curative treatments, though generally, laypeople use palliative and hospice care synonymously.

Communication with patients is a significant barrier to health care, and among hospice settings, professionals frequently use medical or clinical jargon not understood easily by their patient (Pino, Parry, Land, Faull, Feathers, & Seymour, 2016). Another issue of communication is related mainly to minority populations that speak languages other than English, as many hospices in the Las Vegas area are limited in bilingual staff. One study found that many organizations utilize ad-hoc rather than professional interpreters in hospice and palliative care settings which can create mistrust, ambiguity in communication, or problems with adequate decision making (Silva et al., 2016). Silva et al. (2016), used a systematic review of literature in multiple languages from the years of 1960 to 2014, reviewing approximately six databases to compromise their sample of 10 selected articles. Their study indicates that frequently family members, such as children, are used as interpreters, and frequently those ad hoc interpretations do not include medical information that is crucial in making informed decisions about healthcare. Recommendations from previous research to enhance communication among patients and providers include hiring multicultural or bilingual staff, providing cultural and linguistic

training to staff, and utilizing translator services where possible (Tan-McGory & Betancourt, 2014). It would behoove the hospice and palliative care industry to employ those that are bilingual, specifically Spanish speakers, as this is a large population that underuses hospice services.

Personal values and cultural nuances also play a vital role in the utilization of hospice services, and ingrained beliefs create an emotional impact at the end of life, preventing a patient or family from seeking this level of care. Emotions and tensions are already high when someone is ready for hospice care, combined with the issue of family dynamics at the end of life. Families may have personal beliefs such that hospice means the patient is giving up on life or even preferences for life-sustaining treatments, which are incompatible with hospice care (Drisdom, 2013). Such issues are relevant at the end of life and usually, related to cultural or religious beliefs. For example, many African Americans use their spirituality and religious beliefs to pray for healing rather than accepting hospice care (Rhodes, Batchelor, Lee, & Halm, 2013). Drisdom (2013) suggested that nursing and clinical staff can address such issues by providing education regarding the nature of hospice services, quality of care, and ultimately focusing on building relationships with vulnerable minority communities.

# **Importance of Traditions and Practices**

The experience of death is universal and often can be synonymous with the term trauma. Burial rituals, funeral rites, and cultural practices of bereavement establish a sense of order during a chaotic time as well as honoring the deceased. Bereavement is both a complex and personal experience affirming the importance of the person known

and departed while serving as a source of comfort as the bereaved seek to navigate life without their loved one (Simpson, 2013). Within and between cultures are specific practices that honor and support loss in a highly personal way. Coping at the time of loss may seem impossible, though it is a natural progression and way of life that must eventually be faced, the most challenging aspect of grief is the unknown, and traditions, at a fundamental level, serve to comfort many.

Elizabeth Kübler-Ross, a psychiatrist and researcher in the field of bereavement, death, and dying created a model of grieving (in 1969) referred to as either "The Five Stages of Grief," or "DABA" (p. 37-132). Her model describes a nonlinear journey through the experience of loss whereby one begins at denial and ultimately ends in acceptance (Kübler-Ross & Kessler, 2005). Initially, as would be anticipated, a person experiencing loss is shocked by the death, and they move in and out of the stages of grief through their healing process. In denial, a person feels as though the difficulty they are facing cannot be real, refusing to recognize that their loved one has passed away or is critically ill. Once an individual has moved to anger, mixed emotions arise, with the most prominent being the frustration that death has occurred or is on the horizon, common reactions include anxiety, guilt or shame, and a sense of suffering. Bargaining is a stage that one can experience, especially when their loved one first seeks hospice care, often individuals question what may have been done differently or what they could have done to avoid the loss. Among the stages of loss is depression, which, unlike the clinical manifestation, refers to generally feeling saddened by the loss and experiencing triggers. Such a grief reaction is normative and is where the realization that a loved one has passed is recognized. Lastly is acceptance of grief and loss, which means reconciling the reality that the person has passed away and will remain only as a memory.

These stages are experienced differently by specific cultures and by individuals; the process of grief is personal and changes daily until those who remain to process the loss. Further, these stages serve merely as a guide to grief and are not heavily supported by empirical research, though the model is often an educational tool in social service programs and hospice care (Bonnano, 2009). Prigerson and Maciejewski (2008) sought to explore if processing grief ultimately leads to acceptance of loss using data collected in a previous longitudinal cohort study of 233 bereaved individuals collected between 2000 and 2003. Findings from this study indicated that clinicians and physicians are imperative in assisting with acceptance at a cognitive level; for example, those included in the sample that discussed treatment options and alternatives at length with healthcare providers were more accepting of their situation but also were more likely to have a DNR order. The concept of cognitive acceptance from these researchers' perspective, while closely linked with the Kübler-Ross stage of acceptance, differed primarily in that the stages of grief focus on acceptance from an emotional aspect. To assess for patient emotional acceptance researchers created the Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) scale to measure acceptance; the scale was a twelve-item questionnaire assessing feelings of emotional conflict related to illness, peacefulness, and overall sense of acceptance (Prigerson & Maciejewski, 2008). Their research findings suggest that to grieve successfully, patients and bereaved families must seek acceptance of losses, thereby reducing adverse grief reactions.

The stages of grief are useful for understanding the differences between normal and complicated grief reactions, especially in the context of cultural norms. For example, some Western cultures imply that one must remain strong when grieving while other cultural nuances dictate the expression of raw emotion such as crying, lengthy bereavement rituals, and commemorations of the deceased (Holte Kofod, 2017).

Common reactions to grief include possible visual or auditory hallucinations, questioning one's values or belief system, emotional symptoms including anger, relief, or guilt, and psychosomatic symptoms such as poor appetite, social isolation, and physical symptoms of anxiety (Grosz, 2003). In hospice care, while common grief reactions occur, tensions are often high due to the phenomenon of anticipatory grief where families and patients are anticipating impending loss, which may heighten grief reactions or compound losses (Johansson & Grimby, 2011). While not always the case, the stages of grief can be experienced as pre-bereavement, when an individual begins to grieve the loss before it occurs, such as when hospice first admits a loved one.

## **Social Work Role in Hospice Care**

Social workers are members of the multidisciplinary team and are assigned to each admitted hospice patient to assist with continuity of care (K. Hill, personal communication, February, 2018). Historically, a general practitioner needed only a bachelor's degree in social work to handle hospice care (Jones-Moore, 2016). However, the more recent heavy emphasis on recognition and understanding of medical jargon in the profession has raised the education standard for a hospice worker to a Master of Social Work degree (Jones-Moore, 2016). Per Medicare regulations, social workers are

required to visit a patient within the first five calendar days of admission to assess for relevant psychosocial issues and any community-based needs (NHPCO, n.d.). Hospice organizations have their own rules for how often a social worker should have contact with a patient; generally speaking, social workers typically visit at a minimum once per month and more if the need arises (NASW Center for Workforce Studies & Social Work Practice, 2010). Caseloads for each social worker in Las Vegas range from eighteen to thirty-five patients, depending on the agency, and include tasks such as assisting with family-dynamic issues and advocating on behalf of the patient (K. Hill, personal communication, February, 2018). Most social workers in hospice settings cover a daily 8:00 am to 5:00 pm shift in hospice settings but are also expected to participate in a rotating on-call schedule for after-hours emergency needs (K. Hill, personal communication, February, 2018).

Among hospice settings, there is no "typical day," as social workers must remain flexible if the death of the patient becomes imminent or the patient passes suddenly. In such an event, social workers provide immediate crisis intervention, educating the family on what to expect and when to call hospice, reviewing current final arrangement and encouraging pre-planning as applicable (Gwyther et al., 2005). Crisis intervention includes prioritizing tasks, recognizing when respite services are needed, advocating for such services on behalf of the family, and emergency placement in the event of significant changes or funding issues after a sudden loss (Myer et al., 2013). During the progression of illness and throughout hospice care a social worker assists in resource development and strengths identification offering bereavement counseling and

connecting families to relevant resources (Chowns & Richardson, 2016). Lastly, a family generally has the support of the social worker and hospice bereavement services for one year following the death of a loved one (National Hospice and Palliative Care Organization, 2008). Social workers frequently assist with survivor's benefits, providing information about places to contact once a death has occurred, and even offering additional support through group facilitation regarding loss and recovery (Boucher, Kuchibhatla, & Johnson, 2017). Since social workers have so many interactions with families and patients in hospice settings, they must understand specific cultural reactions toward grief and beliefs surrounding hospice care.

#### **Summary**

In this section, the purpose of the study, relevance to the field of social work, and the potential benefits of the study were identified. As previously mentioned, there is minimal research specifically exploring social workers' attitudes, beliefs, and opinions regarding cultural humility in hospice practice. The benefit of such a conceptual framework in end-of-life care is that there are many culturally informed dynamic concerns, and social workers are encouraged to continue to challenge their own beliefs, reflect on their cultural identity, and recognize the importance of intersectionality as it relates to the end-of-life process. Ultimately, focusing on such issues may benefit the terminally ill patient by encouraging social workers to practice culturally appropriate models of care. These specific considerations further assist social workers in encompassing a more comprehensive and individualistic approach to each patient they may be working with which has the potential to improve quality of life at the end of life.

In section two, the research design, methodology, and rationale are discussed as well as relevant social work values and ethical considerations.

## Section 2: Research Design and Data Collection

The purpose of this project is to explore social workers' knowledge in working with terminally ill patients in a hospice setting and provide insight into practitioner development of cultural awareness, including agency-specific standards, and how practitioners feel their views of cultural humility impact the terminally ill patient. Further, research from this project may encourage continued development and understanding of cultural practices thereby enhancing overall standards of practice among hospice professionals. The questions for research are: (a) How do social workers in Nevada define cultural humility in the context of hospice social work practice? (b) What values or principles do social workers in Nevada consider most important in providing culturally appropriate care to hospice patients? and (c) In what ways have hospice social workers in Nevada implemented a cultural humility stance within their practice? In this section of the proposal, I offer insight on the context for this study, including information on the clinical practice problem, an outline of the research methodology for addressing research questions, and presentation of ethical considerations as they directly relate to the project.

The purpose of this research is collaboration with social work professionals employed in a hospice setting on their knowledge of culturally informed practices and use this information to gain insight into what specific values or principles are relevant to culturally appropriate care, and how social workers feel their understanding of cultural humility impacts the terminally ill patient. For this study, participants will expand upon their knowledge base of culture as a social construct and how that knowledge impacts service delivery towards a terminally ill patient. Participants will further provide their

understanding of cultural humility as a concept and how the development of cultural humility may positively impact end-of-life care.

The emphasis of this project is to identify how social workers develop cultural standards of practice, personal views of cultural humility and the impact on care provided, and determine what social workers consider to be essential elements to provide culturally appropriate care that is tailored to the individual patient. Findings from this project will provide a deeper understanding as to how social workers conceptualize the framework of cultural humility, what values or beliefs they have regarding this concept, as well as how they implement cultural humility in working with terminally ill patients. These findings may then further the body of knowledge and potentially assist in developing a greater understanding of cultural nuances utilizing a social work strengths and empowerment based perspective while also allowing social workers to express their views about the clinical practice problem identified. Lastly, recommendations from this research are anticipated to provide a foundation for future studies, promote the development of cultural humility in practice, and the improvement of interventions in service delivery.

The clinical social work practice problem is the implementation of culturally appropriate care towards hospice patients. My professional experience and research conducted reveal that Las Vegas is a transient city with people of varied backgrounds each holding their own unique beliefs, traditions, and practices. It is anticipated that through this research there may be a need for additional cultural competencies and training provided to those social workers that are employed in hospice settings.

Increasing social worker knowledge of cultural practices, values, and nuances will assist social workers in the provision of culturally informed interventions, thereby improving the quality of life at the end of life.

#### **Research Design**

The research design for this project involves a qualitative approach using a focus group conducted with professional social workers currently employed in a hospice setting in Nevada. Participating practitioners will offer their understanding of the definition of cultural humility, relay what they feel is relevant in terms of professional values and ethics in the provision of culturally appropriate services, and discuss how they implement cultural humility within their practice setting. A qualitative approach allows for a thematic exploration of personal themes that combine to create cultural humility and cultural practices in a hospice setting. Emergent qualitative themes are relevant as culture and practice of traditions, values, and beliefs are often subjective but ultimately impact the end-of-life experience significantly about issues such as advanced directive planning, funeral arrangements, and overall outlook on life.

The specific methodology will involve a qualitative focus group conducted with eight to twelve community-based social workers currently employed in a hospice setting and with experience of at least three years. The size of the focus group will be limited to the number of social workers within the identified practice area who are willing to participate in the project voluntarily. The emphasis of the focus group will include areas where cultural humility and culturally informed practice can be expounded upon or may be improved as well as any agency-specific policies or practices that relate to the

implementation of cultural humility in practice. It is anticipated that social workers participating in the focus group will offer insight into specific cultural considerations that are relevant for hospice practice and ways in which they implement culturally appropriate interventions with those that are of different ethnic backgrounds based upon their cognizance of cultural humility.

Focus groups are a commonly used qualitative method which is prominent across various disciplines since they allow the researcher to collect a large amount of data in a rather short amount of time (Breen, 2006). Since this is a qualitative method, it is beneficial when research is conducted to investigate participant perceptions, interpretations, or thoughts about a specific topic. Focus groups have several advantages, including the ability to quickly obtain beneficial information for research purposes and low-cost design, and this method offers a broader scope of data gathered (O. Nyumba, Wilson, Derrick, & Mukherjee, 2018). Disadvantages, however, include possible distractions from the topic of focus, difficulty with analysis, and the group setting may be intimidating to some participants (Acocella, 2011). One study researched the standards for conducting a focus group utilizing a thematic analysis of 40 focus groups and critical review of approximately 62 books dedicated to focus groups in research (Guest, Namey, & McKenna, 2016). The researchers found that the average focus group was 1 hour and 50 minutes in duration and nearly all had six to eight participants. Because I seek to understand social worker perspectives of cultural humility as implemented in hospice, the focus group method would be most beneficial as it allows for broader exploration of participant insights.

## Methodology

## **Prospective Data**

Data was collected through a focus group that included participants currently employed in a Las Vegas hospice care setting with three years or more experience, and possession of a master of social work (MSW) degree or higher. The focus group encouraged a collaborative dialogue which provided insight into relevant social issues related to culture, grief, bereavement, and burial practices. I was specifically interested in participant understanding of cultural humility as a standard of practice and how participants implement a cultural humility stance when working with patients of diverse ethnoracial backgrounds.

#### **Participants**

The sample comprised current Las Vegas social workers employed in a hospice setting that have at least three years' experience working with terminally ill patients and possess, at the minimum, an MSW degree. The sample included nine social workers; and because hospice care, at times, may be unpredictable, time considerations for participants were accounted for with the establishment of a two-hour maximum timeframe for the focus group.

The sample was recruited through my connections as a former hospice social worker and outreach via telephone calls or e-mails to local hospice care agencies inquiring about potentially interested participants. Once an initial pool of participants had been identified, I submit an e-mail to my point of contact at the partnership organization which informed potential participants of the purpose of the study, participation

procedures, and information regarding informed consent and confidentiality. Participants were provided with the opportunity to ask additional questions that they had and once they consented to participation, they were offered the consent form to complete and sign.

#### Instrumentation

To ensure that the time requirements are both respected and maintained, I had created a list of potential questions to ask participants which allowed for a semi-structured conversation that is most relevant to the topic of interest for this project.

Before completing the focus group analysis, I provided a verbal reminder of participation procedures, informed consent, and confidentiality practices. Further, participants were educated that conversations were recorded, transcribed into a written transcript, and later codified to identify emergent themes of the focus group.

Because cultural humility is a loosely defined concept, I provided participants with a shared working definition for this study. Participants were also questioned regarding their conceptual understanding of cultural humility and provided with an opportunity to clarify anything they did not understand. In group facilitation, the following questions were asked of participants to assess practitioner knowledge, identify common interventions and care standards, and to determine how to improve current practices:

- 1. What is your understanding of the concepts of cultural humility and cultural competence?
- 2. In what ways do the concepts of cultural humility and cultural competence differ?

- a. In what way are the concepts the same?
- 3. What education and training did you receive regarding cultural factors at the end of life?
  - a. Was this training or education offered through a BSW or MSW program, or was this through your organization, NHPCO, or continuing education credit?
- 4. How do you continue to develop cultural sensitivity and awareness throughout your practice?
- 5. In what way is cultural humility relevant to hospice care in your perspective?
- 6. What do you consider to be most important in providing culturally relevant and sensitive interventions/care to your patients?
- 7. Do you think your views of cultural humility have an impact on the hospice patients' end-of-life experience, how or how not?
- 8. Are there any additional comments on cultural humility within hospice practice?

Data was collected utilizing a focus group to identify emergent themes on cultural practice in a hospice setting. Semi-structured interviews for this research comprised open-ended questions preselected for participants, allowing for a focused topic and participant development of conversation. Such a structure facilitates in-depth exploration of participant responses and flexibility during the interview process.

#### **Data Analysis**

Data was transcribed, analyzed based upon content through categorization of participants' verbal and behavioral data, and then codified into a single codebook, first by open coding and then again by selective coding, to focus on the development of themes identified among participant responses as well as emergent patterns. The goal is identification of keywords and concepts that participants describe throughout the focus group. From here data was summarized in light of the research questions and aim.

Once data was collected through the focus group process, I employed a secure transcription service to have data transcribed in preparation for analysis. I then utilized an open-coding method to interpret data by labeling concepts and developing categories based on participant responses identified through the transcription process. Selective coding followed to allow me to conglomerate, emphasize, and organize codes into coding categories utilizing a codebook. Four to five emergent themes were selected from the codebook by identifying patterned ideas or concepts. After themes had been identified and coded, I categorized all information obtained by theme classification. Lastly, I reviewed codified data and interpreted the central idea, summarized the occurrence of concepts, and conclusions discussed by participants as related to themes identified (Maguire & Delahunt, 2017). From these interpretations, data that substantiates the relevant themes was analyzed, and conclusions were addressed as relevant to answering the research questions of this project.

Rigor is the process that removes as much as possible, potential biases or editorial information from the researcher's perspective from the research (Cypress, 2017).

Validity in research is the process of outcomes which accurately reflect the data (Noble & Smith, 2015). Dialogue on validity within the context of a qualitative design may be complicated, as this research design is often used to gain perspective from participants and therefore such research is often open to subjective interpretation (Whittemore, Chase, & Mandle, 2001). Findings from this project explore social worker's understanding of cultural humility as a concept by encouraging their sharing of meaning and definition, as well as in-depth analysis of their knowledge of cultural humility within their practice setting.

Once the data collection phase was complete, I analyzed information received from the focus group with information obtained from the literature for a comprehensive comparison. Member checking is a process where data attained is returned to the participant(s) to validate data and ensure accuracy in responses (Birt, Scott, Cavers, Campbell, & Walter, 2016). Participants received a copy of the focus group transcript to review and ensure that information collected, transcribed, and then analyzed was accurate, ensuring the findings are credible, trustworthy, and objective.

Trustworthiness in qualitative research is a concept that refers to a study's validity and reliability, as qualitative researchers do not utilize quantitative methods within their data collection or analysis (Nowell, Norris, White, & Moules, 2017). Researchers establish confidence in their findings by ensuring that their methods are trustworthy and come solely from participants involved in the project (Anney, 2014). Trustworthiness is displayed through recognition of various perceptions and values as related to the research questions of this project, as well as through a discussion of findings which accurately

displays the participant responses and standpoints. I utilized the method of triangulation to indicate to the reader that these findings are both credible and accurately reflect information gathered from participants. Triangulation is the process whereby data collected will be cross-verified through not only my interpretation but verification of accurate reflection of information by participants involved through their review of the focus group transcript (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Further, I identified all steps of analysis to portray how data was transcribed, reviewed, and determined to be meaningful as related to answering the research questions identified.

#### **Ethical Procedures**

IRB approval was granted prior to recruitment of participants, data collection and analysis, IRB approval number 06-07-19-0673193, expiration June 6, 2020. A well-established transcription service will be utilized to transcribe recorded audio into a text based transcript. The company utilized for transcription will be Go Transcript, which requires all employees to sign a non-disclosure agreement; data will be further protected by cutting files into five-minute intervals and divvying up each interval to an entirely different transcriptionist. Because the file is made into various sections, the same transcriptionist is not allowed to work on multiple sections of a larger file, further protecting the confidentiality of participants. Transcriptionists are monitored and, once transcription is complete, the file is removed from the system.

Confidentiality is the concept whereby an individual's privileged information is respected and maintained private; this information includes participant identifiers such as

name, gender, address, and date of birth (Kaiser, 2009). Such information will be protected and removed from the final stages of study as it is irrelevant to the research questions identified. Any personally identifying information (PII) that I gather is maintained during the data collection period of this study only in a password-protected Excel spreadsheet, which only I have access to. Upon project completion, this information is retained for the minimum required five years as an encrypted and password-protected file and then securely deleted. Further, as the codebook was created from this spreadsheet, I utilized pseudonyms to label and de-identify the data.

Additionally, participants were provided with informed consent (Appendix C) before participation which identified potential benefits or risks of participation, ability to participate voluntarily and end participation at any time without repercussions, information about compensation, time commitments, and contact information to reach the researcher.

In upholding the NASW Code of Ethics standard 1.07a, participants were informed in advance of their privacy rights as well as provided with a verbal review of informed consent and how confidentiality is maintained throughout the project.

Information regarding participant informed consent included identification of any possible risks of participation, what the participant can expect from their participation as well as what participation entails, and rights of confidentiality and privacy. Lastly, participants were informed that participation is voluntary. During the review of informed consent and confidentiality, participants were given opportunity to ask any additional questions they had on either subject.

# **Summary**

In this section, the recruitment of participants, as well as requirements of participation, were outlined. The study's methodology and instrumentation were discussed in detail with a focus on relevant research values such as confidentiality, informed consent, and risk to participants. Briefly, data analysis procedures were described including the use of a codebook to categorize data and subsequent thematic analysis. In the following section, I will present my findings for consideration, describe data analyses techniques and procedure, and report how such findings answer the research questions.

# Section 3: Presentation of Findings

The purpose of this study was to explore how hospice social workers in Nevada define, comprehend, and employ a cultural humility stance within their practice setting while working with terminally ill patients.

Research Question 1: How do social workers in Nevada define cultural humility in the context of hospice social work practice?

Research Question 2: What values or principles do hospice social workers in Nevada consider most important in providing culturally appropriate care to hospice patients?

Research Question 3: In what ways have hospice social workers in Nevada implemented a cultural humility stance within their practice?

Action research methodology using a classic qualitative design was used to collect data, via a focus group with nine social workers actively employed in a hospice setting, with an MSW degree, and a minimum of three years' experience employed in hospice care. Convenience sampling methods were employed to recruit volunteer participants from the partnership organization; this is a nonprobability sampling method where potential participants that meet specific predetermined criteria are included for the study (Etikan, Musa, & Alkassim, 2016). Transcription of the focus group discussion allowed for quick coding and thematic analysis, which assisted in developing pertinent research conclusions. Thematic analysis was used to identify relevant themes among the dataset, used to recognize the meaning of the codified data. I utilized a transcription service called GoTranscript and a qualitative data analysis software ATLAS.ti to auto code themes. Section 3 outlines the data collection, analysis process, and validation

procedures. In this section, I also address limitations of the study, provide a description of relevant findings as well as unanticipated findings, and finally conclude with a summary.

## **Data Analysis Techniques**

Before approval from the Walden University Institutional Review Board, I telephoned approximately thirty-seven local Hospice organizations to ascertain the organization's willingness to participate in my potential study. From this initial contact, I had three potential agencies which would allow recruitment once I passed the rigor of the Institutional Review Board. Upon approval by Walden University's Institutional Review Board (2019.06.07 16:16:11-05'00'), I began the recruitment process of social workers with a master's level education and a minimum of three years' experience in a hospice setting using my point of contact at the partnership organization. I used the point of contact at the agency as a gatekeeper for all information, submitting to them the participation invitation letter to forward to social workers at their agency. From this invitation, approximately fourteen social workers expressed interest in participating, however, several did not work in hospice, but other areas such as palliative care and several only held Bachelor's level education. Of the fourteen a remaining ten social workers expressed interest in participating upon receipt of their invitation e-mail. I scheduled the focus group via e-mail with the point of contact who coordinated through the organization a secure conference room where the focus group could be held. Of the ten social workers who expressed interest in participation, nine attended the focus group.

The semi-structured focus group was held in late June of 2019. Prior to the start of the focus group, I reviewed the consent for study again with the participants and e-mailed

a link to an online anonymous format ten-question demographic survey to my point of contact to be shared with the participants for completion. Participants were also offered the opportunity to ask any initial questions prior to the start of the focus group, and this opportunity was again granted at the end of the focus group section. All participants completed the demographic survey by the end of the day on which the focus group was held. Data was collected over a period of 51 minutes and 40 seconds. I facilitated the focus group, asking participants a set of ten questions to provide structure to the process, though several questions led to follow-up questions for additional information and clarification, which contributed to the validation of the research.

Participants were given pseudonyms (Feygl, Libke, Tzipi, Bluma, Raisa, Asnat, Dreize, Sittel, and Ze'ev) to protect their confidentiality and ensure anonymity while assisting with data collection and analysis. I utilized a WJLING audio recorder to record the focus group and then had the recording transcribed using a secure transcription service through GoTranscript. Once I received the transcription, I reviewed it twice for accuracy; then I reviewed once more, listening to the focus group recording while reading the transcription to ensure precision. I completed making adjustments as needed since some of the incorrect transcription from the service used was related to clinical jargon and I removed all names mentioned, and assigned each participant a number to deidentify the data. Once I updated the transcript, I submitted it to the point of contact so participants could review the data to further validate the data and allow for triangulation using a member-checking technique. Member checking is the process whereby

accuracy and credibility of data transcribed (Birt, Scott, Cavers, Campbell, & Walter, 2016). Though I did not receive any feedback from participants in this process, I again read the document before beginning my initial coding.

After I had read the document four times, I read it once more to highlight important comments and prominent themes using thematic analysis. Thematic analysis is a multi-step process encompassing six major steps; becoming familiar with the data, creating initial codes, labeling codes by initial themes, reviewing themes identified, defining and then naming the themes, and, lastly, conducting analysis through a report (Braun & Clark, 2013; Maguire & Delahunt, 2017). I then uploaded the document to my personal ATLAS.ti server and allowed the system to auto code by prominent themes and checked these codes against my own, making note of matching relevant statements.

Coding was conducted by question through comparing prominent responses that participants made, with attention on recurring themes identified through participant responses with an initial list of fifteen codes. Creating these themes allowed for further exploration and in-depth analysis of the focus group discussion. I reviewed all themes and compared them to the data set overall ensuring cohesion and relevance to the research questions presented for this study. I then grouped all statements by relevant theme and color coded. Initially, I identified eleven themes with five or more relevant quotes to support each theme, but I then narrowed down to the most relevant themes based upon the most commonly identified key words and themes participants addressed which served to answer my research questions. Five major themes were identified using this process: (a) individualized culture, (b) respect for others, (c) team-oriented approach,

(d) intuitive implementation of cultural humility, and (e) lack of formal training and integration of hands-on experience.

#### Limitations

While there were many strengths within this study, there were also limitations. First, I as the researcher asked clarifying questions to participants in the focus group format. Clarification has the potential for the researcher to unintentionally influence participants with non-verbal cues and body language, though I was careful not to do this while clarifying relevant points made by participants (see Tausch & Menold, 2016). Another limitation is that because focus groups generally include smaller sample sizes, they may not be a good representation of the larger population, and this is especially true of this study as the Las Vegas community differs significantly from others since it historically has been rather transient (Dworkin, 2012). Lastly, participants may feel pressure from their peers to give similar answers or they may generally be uncomfortable with speaking in front of other participants.

## **Demographics**

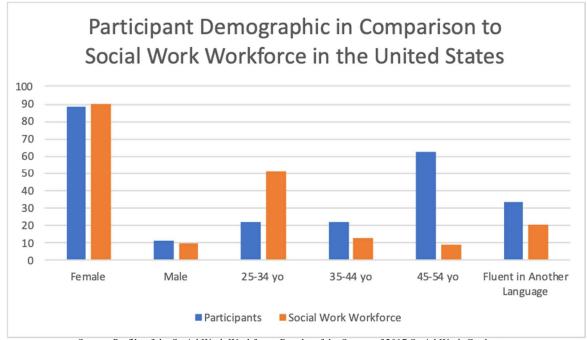
Nine participants were included in this research study. All were given a participant identification number to de-identify the data and protect their confidentiality. Eight of the social workers were female, and one was male. Six participants self-identified as Non-Hispanic White or Euro-American, two as Latino/a or Hispanic American, and one participant identified as East Asian or Asian American. All nine participants reported speaking English fluently, two identified Spanish as a fluent

language, and one also spoke Danish. Two participants were born outside of the United States.

One participant held an LCSW license, and the remaining eight were LSWs at the master's level. Six participants reported no additional credentials, and three indicated that they held either a CHP-SW or ACHP-SW credential in addition to their master's level license. All participants held at the minimum a Master of Social Work degree, graduating from CSWE-accredited social work programs, and one participant indicated that they were returning to school to complete a doctoral program in a related field.

Two participants were 25 to 34 years of age, two participants were 35 to 44 years of age, and five participants were 45 to 54 years of age. One participant reported 3 to 4 years of hospice experience, one reported 5 to 7 years of experience, three reported 8 to 10 years of experience, and four reported 10 or more years of experience in hospice. Lastly, all participants reported that they worked a full-time employment status of approximately 40 hours or more per week, though the partnership organization does have social workers employed on part-time and PRN basis. Though not all demographics requested for this study are relevant to the social work workforce report, I completed a graph for relevant comparisons and to validate credentials of the participants (*Figure 2*).

Figure 2: Study Participants' Demographics in Comparison to Social Work Workforce in the United States from Profile of the Social Work Workforce (2017).



#### Source: Profile of the Social Work Workforce; Results of the Survey of 2017 Social Work Graduates.

# **Findings**

In this study, I focused on cultural humility in hospice social work practice among a sample of social workers in Las Vegas, Nevada. I specifically focused on areas of practitioner definitions of cultural competence versus cultural humility, what values or principles are most relevant to offering culturally sensitive care to terminally ill patients and how social workers implement a culturally humble stance in hospice. In this investigation, I focused on participant responses—their own definitions, understanding, and comprehension of cultural factors at the end of life. Further, I investigated potential learning and education opportunities for social workers on the intersection of hospice care and diversity issues.

As previously mentioned, I utilized ATLAS.ti to soft code the data and then reviewed preliminary codes to identify prominent themes. Perhaps most interesting in the focus group dialogue was that only two of the nine participants were familiar with cultural humility as a concept, but all reported implementing this stance within their daily practice intuitively. Additionally, participant responses point to a need for ongoing communication with the hospice care team, continued introspection and awareness of one's own cultural and diversity issues, as well as those social workers who are empathetic and culturally sensitive appear to be inherently drawn to the field of hospice.

#### **Identified Themes**

Data collection and analysis revealed an initial list of 11 themes introduced by participants, though through several reviews of the transcript it became abundantly clear that many of these themes were interrelated and, therefore, five synthesized themes were identified. These themes all have a direct connection to the research questions for this study, and data collected supported the need for a cultural humility stance in working with terminally ill patients within a hospice setting.

These themes permeated most of the participant responses and seemed to intrinsically build upon one another:

Theme 1: Individualized culture.

Theme 2: Respect for others.

Theme 3: Team-oriented approach.

Theme 4: Intuitive implementation of cultural humility.

Theme 5: Lack of formal training and integration of hands-on experience.

The themes are further expanded upon below and participant responses are denoted to support the themes identified. It is important to note that minor editorial changes were made as necessary to some responses to ensure that the responses read grammatically and appropriately. All participants were given pseudonyms to protect confidentiality and privacy yet allow for review of the relevant themes identified and further protect the trustworthiness of the study to ensure that results were not merely from several very vocal participants but rather a mixture of various participants. Pseudonyms given were of a Yiddish theme and held true to the initial reason why this author chose this topic for study; pseudonyms were Fegyl, Libke, Tzipi, Bluma, Raisa, Asnat, Dreize, Sittel, and Ze'ev. Overall, most participants were active in the conversation but a few were less vocal in their responses, electing to agree with other participant responses.

### **Theme 1: Individualized Culture**

One major theme identified was that generalizations cannot be made and while everyone identifies with a specific culture or has an affiliation, this does not mean that people among or within the same cultures will have the same identification or understanding of their culture. Nearly all participants agreed that there was a need to recognize each individual as just that while also understanding that each culture is unique. Participant Bluma indicated the following:

I would like to point out because I find that every family unit has their own culture... and we establish, maybe in the assessment, regardless of someone who is Caucasian or Hispanic. You have a different culture within socioeconomic status and those groups, I find answering those questions in such a broad generic

way, almost a little bit impossible because that's why we individualize each assessment.

Other participants, including Tzipi, Raisa, and Dreize agreed and indicated that the social work process is very individualized and respectful of the culture that each patient addresses as relevant and personally important to them. Raisa stated:

In my experience, I found that with every culture in itself is so different. Even this Middle Eastern culture it depends at times for how long they have settled in

United States. It is a language barrier or not and if you not understand something. Some participants, Raisa, Bluma, Feygl, and Libke, brought to light that unlike traditional views of culture, the concept may not just be associated with racioethnic identity, gender, or religious factors but rather affiliated groups such as veterans or LGBTQ (lesbian, gay, bisexual, transgender, queer) individuals. With this identification, it was also made clear by many responses there is a great need to avoid and recognize generalizations. Tzipi was quoted as saying that the organization to which they belong is seeing to recognize the variations between cultural definitions and that overall, they are seeking to become more aware of related issues, "Well, just one group that we're focusing on right now is Veterans as a culture. We're trying to learn more as an organization about Veterans and their needs... it means it's not just like always about race..."

### In the words of Libke:

I think [culture] it's a very individualized [process]. I think the difference in hospice is there are generalizable cultural concerns and things that we need to be

aware of as a generalization but in hospice, you go in with an open, really an open mind because every home, every patient is different.

You can't just say, if you look at LGBTQ as a culture, you can't just say going into that home that every LGBTQ is this way. You can't make that generalization or every time I have a caregiver, a wife from Thailand, every Thai caregiver is going to respond this way. We can't make that sweeping generalization and in any of our homes because every single one of them is different.

Lastly, Dreize brought awareness to the ways in which the term culture can create an inclination to stereotype or overgeneralize inadvertently though people are seeking to understand:

I think cultures are sometimes boxed into stereotypes. When you have some formal setting in teaching because it's very dangerous and it gets in the way too much. That is when people start to get upset too when they are approached enhances that stereotype almost.

Participants had varied views about culture, though one commonality was the importance of culture; Libke, Bluma, Raisa, and Sittel indicated that it is not possible to address the needs of patients without being aware of the family culture as well as the individual identification of the patient's culture. Lastly, all participants touched upon a relevant tenet of cultural humility as a concept throughout their answers with the need for recognizing your own identity, affiliation, and biases through introspection.

## **Theme 2: Respect for Others**

Another theme that continuously was mentioned was that of respecting the patient, family, and process of hospice care. This was identified in eleven different responses by multiple participants throughout the entire focus group as stated by Tzipi:

It just being respectful is the biggest thing to me. Whatever it is that you're there being respectful of them. I think that's a key to having that rapport [with the patient and family].

Asnat, Dreize, Sittel, and Raisa indicated the need to respect the family's right to make choices and recognize that regardless of your professional capacity fundamentally, you are a guest in the patient's home. Feygl went deeper into this concept addressing the importance of recognizing what patients need in order to best help them through their end of life experience:

It's the end of life so you want to make sure that in their last days they are respected and their choices, their culture that we're trying—we're guests in their home trying to help them. We need to understand what they need from us. Being open to what they need.

Tzipi addressed unfamiliarity with cultural practices as using a respectful approach as a cultural engagement tool to develop rapport, build understanding, and show an express interest in the patient's culture.

...If you're respectful to them and ask them and say I'm not very familiar, could you please teach me about it. Most of them are very willing to talk to you about what— I recently had a Baha'i and they love to teach me everything about it

because I'm really not familiar. I learned a lot just because it was— It's something you don't generally have. I had one in 13 years.

Such an approach directly relates to the conceptual framework of this study by treating the patient as the expert in his or her own experience and striving to learn more through engagement. What is most interesting about these responses is that though the participants did not have formal education or training in cultural humility many approached these questions through such a lens.

## Theme 3: Team-oriented Approach

Another critical element of the dialogue was that of the social worker's role engaging with families and patients but also sharing information garnered in the field with the team during weekly interdisciplinary team meetings (IDT). Many participants expressed that a crucial element of hospice efficacy is the ability for the teams to work well together and support one another regardless of the foundations of the support provided. Libke remarked:

I think it's also most important that whatever, since it's typically the social worker that gains this knowledge, that we're sharing that with the team, like the IDT meeting and everything. I make specific notes and even though I'm only given my little checkboxes, I make sure I get the rest of it in there before they move on.

Other participants including Ze'ev, Sittel, Raisa, and Tzipi expressed the need to be communicative with the team regularly even outside of the IDT meetings as information is crucial to providing the most positive experience and culturally relevant care. For example, Sittel indicated:

We have to be [communicative]. It would seem because we can't be the only one who understands this culturally relevant information. For best practices, it has to be shared across the board.

Dreize mentioned that those that are drawn to hospice appear to be more accepting and understanding of difference, "I think generally the people that are drawn to hospice are more open. They're willing to go into the hospice and offer respect, whatever the families need." While Bluma relayed:

Hospice is a team approach. We have different disciplines going to into the home and in our IDT setting this is a confidential environment where we are able to share anything we need to share for the next person to be prepared because sharing information is basically preparing... about what they need to look for in order to be there for [the patient].

Still other participants including Asnat and Ze'ev addressed the relevance of certain characteristics that draw specific personality types to the hospice environment, for example, those that are "more open" or "empathetic" in their communication styles.

Lastly, many participants including Bluma, Feygl, Tzipi, Raisa, and Libke noted that the team approach is a well-known element of the hospice philosophy of care and that those drawn to this type of social work practice appear to be willing to engage in this process.

### Theme 4: Intuitive Implementation of Cultural Humility

Only Libke was familiar with the definitions of cultural humility and competence, mainly because she also has a role as an adjust teacher at UNLV, she states:

Cultural competence says, "I know everything I need to know about your culture." I've done all the studies. Cultural humility is, "I don't know what I don't know, so please, I'm open. You tell me how to approach you."

The idea Libke brought up of "I don't know what I don't know" was prominent in many responses by Sittel, Tzipi, Bluma, and Dreize throughout the course of the focus group. Many participants indicated that while there are many cultural unknowns these are not usually something that can be prepared for therefore, the social worker must implement respect for individualized culture with all patients employing a cultural humility stance in their practice with all patients served. Tzipi stated, "You do this instinctively trying to respect what their choices are and what their family unit wants to do but yeah not necessarily knowing that it's cultural." Dreize added on to what Tzipi stated by drawing awareness to assessment questions and ways which cultural humility is implemented without using labeling terms to avoid or minimize judgment.

...when it's on the assessment as cultural, I don't phrase it that way when I'm talking to families. Is there anything we need to be aware of? Do you normally have prayer or— when someone passes away or anything? I ask those questions without saying is there something cultural we need to know about you? Sittel also shared:

Well, it sounds less judgmental when we avoid that term, cultural—because you're already assuming that I'm different. In that case, you're just saying how do you practice, how can we help you in your tradition?

Most surprising but relevant to the research questions identified for this study is that while many participants were unfamiliar with the term cultural humility, they all expressed regularly implementing this stance with their patients. As the focus group ended, Libke participant remarked:

The concept of cultural humility I think is actually practiced by the majority of hospice social workers without necessarily knowing that that's what we're doing.

Tying cultural humility into the respect theme, one participant drew awareness to the fact that hospice is a one-time opportunity to implement cultural humility, while another participant remarked, "you don't get a do-over..."

Ze'ev also brought awareness to the impact that hospice has on the lives of those served:

It's [cultural humility] so important because this is an event in their life they never going to forget. We have our caseloads and we continue to move on. We move on and we go. For them this is a moment in time, it's going to stick with them forever with the experience that we're providing them and the cultural humility and the respect that we provided you.

Raisa described the development of a positive relationship with the client to which Dreize, Tzipi, and Libke agreed:

Well, if you look at cultural humility with that same concept I said earlier, I don't know what I don't know. Every time I call a family and they say, "Why do I need

a social worker?" Well, I don't know until we sit down and talk. You start the relationship with that open door, you tell me about yourself. It's all based in that humility without ever being necessarily taught.

One important pattern addressed throughout the intuitive process of implementing cultural humility is that these participants are selfless in their profession actions; they seek to care for their patients in the best possible way while developing a thorough understanding of the patient's culture, tradition, and hopes for his or her own death.

## Theme 5: Lack of Formal Training and Integration of Hands-on Experience

Lastly, as anticipated, all participants verbalized that they received minimal formal education regarding end of life care and the intersection of culture. Several participants including Asnat, Dreize, Tzipi, and Feygl reported that they were unable to recall education in their master's-level social work program on either topic or the connection between end-of-life care and culture or diversity. Libke stated:

I actually had a class. I don't know if it was my last semester. It was a cultural competency. That was a really good class actually. It kind of challenged me a little bit because I thought that I knew a lot about my own culture and I found that I didn't. He kind of towards the end of the class I realized he was pushing us towards cultural humility rather than competency. He didn't actually use that term but we all kind of came to that same conclusion. That was really great learning that I could reflect on it. I didn't really understand what it was until I actually started practicing. I thought, "Oh. That's what he meant. I don't even know anything about this. Let me learn it." You can start researching and talking to

families and you can reflect it more and realized, "Well what else don't I know?"

You become more open to being among, having humility about not knowing a lot about different cultures in general. That was interesting though...

Bluma brought awareness to the fact that while MSW programs do not always offer formal education about cultural humility, there are opportunities to develop this skill through continued education credit:

I find the funeral home business has a really high awareness about it and is practicing at least some bigger ones here in town and I've been to a few seminars and I was amazed how much more I could learn about the different rituals...

Raisa noted that there was an elective offered in their BSW program but this was not a mandatory course and that she elected to take this course due to her interests. Others in the focus group, Libke, Ze'ev, and Asant confirmed the course was offered only once annually in the summer term. Feygl reported that though she had been out of school for some time, they went back for a degree in gerontology and that was where the education was for them:

I could say that I've been out of school for a long time, 20 plus years. I think—I don't remember in my social work master's program really ever learning about end-of-life. I went back four years after I graduated social works school to get a MEd in gerontology and that was the only time we talked about end-of-life. That was where I really learned end-of-life but it was all focused on gerontology and not across the races or even children for that matter. I don't remember a lot of it in social work school.

Tzipi pointed out that though there is not always continued education credit or formal education on end-of-life care and culture, a tactile daily learning process takes place in the field:

....One thing is that the education might not be formal but we are educated every day by our—education comes from experience, so it's not formal it's from our patients teaching us and then we're learning.

Ze'ev confirmed what Tzipi stated, expanding on daily knowledge:

The more you do something, the more experience you have, the better you are in the future with dealing with each individual person. Rather than you just getting it out of a book. When you meet that first person you still have to go through the process of learning and doing all that. Definitely being hands on I think.

Libke who is engaged in teaching several courses at UNLV reported that she felt the current education on diversity is somewhat behind and continues to focus on competence in lieu of humility:

I think that formal education is behind. I teach at UNLV and we think about the cultural competence or cultural diversity courses that are offered there, it's still more competence-based versus humility. It's been in most recent times have I even heard cultural humility.

She went on further to discuss where she feels the research is falling short:

...It seems to me that the research, the literature is approaching it from a culturally competent perspective versus the cultural humility. The literature is

asking the question from the perspective of being culturally competent which is not actually the question...

Participants expressed a need for more education regarding end-of-life care but expressed there is value in learning in practicum sites and through hands-on experience within a hospice setting. In their own words' participants described implementing culturally sensitive care using a cultural humility stance without formal education or knowledge that this was what they were regularly practicing with their patients served.

## **Unexpected Findings**

While research and the focus group both corroborated that there is a further need for education on cultural humility at both the bachelor's and the master's level, many participants vocalized that though they were not familiar with the concept formally, they often practiced cultural humility. For example, the common verbalization of "I don't know what I don't know" or general respect for cultures of difference was something that I was not expecting to discover through this project. I also found it incredibly interesting that many of the participants mentioned inherent skills that those employed as hospice social workers seem to have which I had not previously considered. Lastly, whereas I hypothesized that a lack of formal education may cause a barrier between the patient and social worker, the participants expressed the exact opposite. Per their responses, by acting as a casual observer, and admitting what they were unfamiliar with or did not know, they felt more connected to the patient and family served while also learning in a less traditional but more beneficial for their learning style format.

### **Summary**

Currently, education on cultural humility as a practice framework is limited and the research is even further limited when looking at the intersection of diversity issues in end-of-life care. The purpose of this study was to explore how hospice social workers in Nevada define, comprehend, and employ a cultural humility stance within their practice setting while working with terminally ill patients. The participants openly discussed their familiarity, understanding, and formal knowledge of cultural humility as a concept. Further, they discussed the relevance of culture, respect, and introspection in practicing culturally sensitive end-of-life care. The five major themes that emerged from the review of the data collection answered all three research questions but addressed first and foremost that most participants were unable to define cultural humility; social workers in Nevada consider respect, individualized culture awareness, and hands-on training as crucial to providing culturally appropriate care in hospice; and lastly, that unintentionally and without direct knowledge that this was what they were doing, hospice social workers in Nevada intuitively implement cultural humility within their practice by addressing the previously mentioned values. Section 4 will outline and address the application of professional ethics in social work practice, recommendations for social work practice, potential implications for social change, and a summary of the research study conducted.

Section 4: Application to Professional Practice and Implications for Change

The purpose of this study was to examine how hospice social workers in Nevada define, comprehend, and employ a cultural humility stance within their practice setting while working with terminally ill patients. I used a semi-structured focus group consisting of nine participants to collect responses from master's-level hospice social workers. Participants reported no formal knowledge of cultural humility but development of these practices through continued education credit and hands-on experience working in a hospice setting. Section 4 includes my recommendations for social work practice and a discussion of this study's potential implications for social change.

# **Application to Professional Ethics in Social Work Practice**

As previously mentioned, only one participant was familiar with the concept of cultural humility by name and this participant is also a professor at UNLV. My study highlights the importance of increasing social worker understanding and knowledge of cultural humility as a relevant concept and developing standards for education not only about diversity issues but further the intersection of these issues in relation to hospice practice. Such development of social worker knowledge and understanding relates to the NASW Code of Ethics standards 1.04 Competence, 1.05 Cultural Awareness and Social Diversity, 5.01 Integrity of the Profession, and 6.01 Social Welfare (NASW, 2018). Standard 1.04 focuses on ways in which a social worker may become more proficient in terms of their area of practice, development of cultural humility may assist a social worker with this goal. Standard 1.05 and 6.01 both focus on issues relating to diversity and cultural factors, social workers should strive to continuously develop further skills

that may assist in meeting the needs of diverse clients which can be addressed with training, education, knowledge, and implementation of a cultural humility stance as evidenced by several responses of participants. Lastly, standard 5.01 relates to the findings of this project by encouraging social workers to continue consulting with others in the field and expectations that social workers will contribute to the knowledge base of social work practice which this project exemplifies.

These standards were further highlighted in my study through identification of the lack of training outside of elective courses for diversity issues at the end of life, education on such practice concerns will overall benefit the general knowledge base for social workers and encourage continued development of diversity competencies. These findings related to hospice social worker practice by showing the need for further education standards specifically in MSW programs as these are the terminal practice degree and standard requirement for those employed in a hospice setting. It is my hope that through contributing to the overall body of research this project may not only assist with development of social worker understanding and engagement in hospice practice but further encourage research interests as they pertain to social work practice and end of life care.

The study also brought awareness to the practicality of the practicum and internship experience for hospice social workers as many participants reported this is where most of their knowledge came from. The findings strengthen the team-oriented approach of the hospice philosophy of care while placing particular importance on enhancing respect for other cultures and recognizing the individual culture of each patient

and family unit. Lastly, participants addressed the urgency to not generalize experience or practical knowledge as each experience is unique.

#### **Recommendations for Social Work Practice**

A formal definition of cultural humility should be developed at a national level either through the NASW or individually addressed through the agency so that there may be a standard understanding of the concept. While it was anticipated that many participants would not know the definition of cultural humility and the study did confirm this hypothesis, what was not anticipated was that hospice social workers would intrinsically implement such cultural practices. It is also recommended that policies are developed to address the education of such cultural practices in end-of-life settings to ensure that this is a standard and not just unique to this population of participants. For example, perhaps hospice organizations will be able to include findings from NHPCO's Diversity Initiative in trainings for current and new staff. Another suggestion would be subsidized cost for CEU events that focus on end of life care and diversity specific issues which not only contribute to overall practice standards but also with social workers developing a more comprehensive understanding of intersectionality among this vulnerable population. Lastly, it is my hope that the findings from this study will be used to benefit future studies exploring the relevance and prevalence of cultural humility among hospice and palliative care settings.

I also recommend that social workers educate others on their hospice teams, such as the doctors and nurses they interact with regularly, about the intersectionality between end-of-life practices and cultural affiliations where needed while striving to be respectful

and avoid generalizations. A pertinent theme of lack of formalized education ran through the group discussion and, therefore, CSWE and other accrediting bodies should seek to implement policies where cultural humility at the end of life are addressed. In many states there are great benefits for participating in Title IV programs to develop a more comprehensive understanding of child welfare and the social worker role. I think it would be a great benefit to many to offer similar programs for those interested in hospital social work practice, and end of life care such as hospice or palliative settings.

In my own practice, this information will be greatly beneficial as more recently I have received a promotion to compliance officer within my current organization. A fundamental element of my new role is to train other social workers, clinical professional counselors, and marriage and family therapists regarding HIPAA, compliance, and diversity issues. The knowledge garnered from my capstone project will assist me and targeting specific competencies and gaps of knowledge as many of the participants expressed there was no formal education regarding cultural practices other than elective courses. At my current agency, we see various populations and there is a great deal of diversity, it is my goal to create a training of diversity issues and incorporate this into our monthly hour of supervision which is required for all clinical staff regardless of licensure status.

The findings from this study may be specific to hospice social workers but this is a topic which can benefit anyone that is engaged with diverse patients. It is beneficial for most medical and mental health settings as there is not a "one size fits all approach" and the findings from this project further indicated this. In terms of a more macro lens, as

previously mentioned we are living in a time where society overall is aging, it is critical that CSWE and other prominent organizations that accredit institutions of learning develop programs similar to Title IV which target those that have interests in working with geriatric populations.

Limitations of this study included that I as the researcher clarified comments from participants while among the group setting however, I attempted to ensure that I was not providing cues or nonverbal responses to the participants. My sample was comprised of eight females and one male, though there was varied experiences among the sample nearly all had only interacted as social workers in a hospice setting which may not be representative of social workers involved in service delivery within the hospital or outpatient mental health settings. Lastly, I completed a review several times of the focus group transcription and once participants were assigned pseudonyms I submitted the transcript to them for review to ensure trustworthiness, though I did not receive any feedback which may impact this element of the study and contribute to the limitations. My recommendation for future studies would be to replicate the study to include other states, such as California, Arizona, Florida, and Utah, which also have a significant population of older adults to determine generalizability to other populations.

Dissemination of the findings of my study will allow for development of competencies and culturally informed practices among hospice social workers from the knowledge obtained through the focus group. In my analysis, I addressed clear themes that were prominent throughout my review of the data collected, these themes address relevant issues in implementing and maintaining cultural humility in a hospice setting.

Sharing the findings of this study with not only my partnership organization but with other local hospice agencies may also contribute to the development of standards of practice. Finally, publication of this project allows other agencies outside of Nevada to access the information and make relevant changes to improve cultural awareness, practice, and policy among social workers in hospice settings.

## **Implications for Social Change**

This study has potential for positive change not only for hospice social workers but also for the terminally ill patients that they serve. The study indicates that social workers are versed in sharing resources, recognizing difference, and implementing a respectful stance when encountering unfamiliar issues. However, it would behoove the field of hospice social work practice to develop relevant competencies to train and educate social workers. Such implementation would benefit those that are ruling out interest in hospice social work but also serve to develop the knowledge base and understanding for those that continue in this field of practice. This may also assist with developing evidence-based practice standards for working with terminally ill patients using a culturally focused lens.

### Micro Level

Through recognizing the need to develop further education as a standardized practice, this may assist in developing a stronger rapport with the terminally ill patient on a micro level. Such knowledge and understanding of relevant end-of-life issues as they relate to cultural practices may also assist the social worker in employing a strengths-based perspective focused on the patient's resilience and current supports in place. Lastly,

increasing social worker understanding of how to implement cultural humility through relevant interventions may strengthen the interventions used, improve respect towards the end-of=life process, and allow for a more engaged and open experience for the patient and the family unit.

#### Mezzo Level

At a mezzo level, hospice agencies may consider implementing regular training on cultural factors at the end of life. The organization that I partnered with on this project is well known for their focus on diversity and education, they also have two departments focused on each issue separately but also these departments regularly collaborate on relevant concerns. One participant noted in the focus group that there was a recent training offered through the organization which focused on Chevra Kadisha practices of the Jewish faith; while this is beneficial education, not all hospice organizations offer such training and those that do are not always consistent in their offerings. At a mezzo level, having regular group interaction for training and education can be beneficial; further, allowing multiple disciplines to interact with one another only strengthens the information shared.

#### Macro Level

At a macro level, there needs to be policies implemented within the CSWE that focus on developing end of life and cultural competencies in CSWE accredited social work programs both at the bachelor's and master's level. The NASW has already begun to shift away from the term *competence* and encourage the use of humility practices as evidenced in the literature review. Lastly, the NHPCO offers information regularly

through diversity initiatives and training opportunities to hospice organizations that are interested in developing these competencies. Such practices should continue to develop social worker practices, interventions, and cultural engagement in end-of-life care.

### **Summary**

The purpose of this study was to explore how hospice social workers in Nevada define, comprehend, and employ a cultural humility stance within their practice setting while working with terminally ill patients. Findings from this research indicate both social worker knowledge, lack of formal education, and recognition of individual culture impact the delivery of cultural humility in hospice settings. These findings are somewhat limited however, as the sample size was only nine participants, all employed at the same hospice agency in urban Nevada. Though the information garnered in this study is encouraging, it is not generalizable statewide nor nationally. Further research is needed to assess the capacity for implementation of policies and practices that target relevant diversity issues and cultural humility enactment at an organizational level. Social workers, as the participants expressed, are engaged in this process by advocating not only for those served but also for themselves and the profession overall.

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## Appendix A: Demographic Questions

- 1. What is your age?
- 2. What is your ethnicity?
- 3. In which country were you born?
- 4. What is your gender?
- 5. Which languages do you speak fluently?
- 6. What is the highest degree or level of school you have completed?
- 7. What license do you currently hold?
- 8. Do you have any additional credentials or certifications in hospice social work practice (i.e. CHP-SW or ACHP-SW)?
- 9. How many years of experience do you have?
- 10. What is your employment status (i.e. FT, PT, PRN)?

## Appendix B: Focus Group Questions

- 1. What is your understanding of the concepts of cultural humility and cultural competence?
- 2. In what ways do the concepts of cultural humility and cultural competence differ?
  - a. In what way are the concepts the same?
- 3. What education and training did you receive regarding cultural factors at the end of life?
  - a. Was this training or education offered through a BSW or MSW program, or was this through your organization, NHPCO, or continuing education credit?
- 4. How do you continue to develop cultural sensitivity and awareness throughout your practice?
- 5. In what way is cultural humility relevant to hospice care in your perspective?
- 6. What do you consider to be most important in providing culturally relevant and sensitive interventions/care to your patients?
- 7. Do you think your views of cultural humility have an impact on the hospice patients' end-of-life experience, how or how not?
- 8. Are there any additional comments on cultural humility within hospice practice?